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ABSTRACT

The handbook, an outgrowth of a project involving 8-13 year-old siblings of handicapped children and their parents, describes ways to implement sibling programs. Problems facing siblings are reviewed, including overidentification, resentment, and embarassment. Guidelines for conducting "sibshops" are offered with information on five goals, such as providing opportunities to learn more about implications of handicaps and to meet other siblings in a casual atmosphere. Suggestions are also presented for discussion activities designed for both siblings and parents. Such discussion activities for siblings include situational role playing and open discussions. Guidelines for conducting information and recreation activities are also provided. Three pages of references are included, as well as a four-page list of "Books about Handicaps for Young Readers." (CL)

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SIBSHOPS

A Handbook for Implementing Workshops for Siblings of Children with Special Needs

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SIBSHOPS: A Handbook for Implementing Workshops for Siblings of Children With Special Needs

by Donald J. Meyer
Patricia F. Vadasy
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INTRODUCTION

The book you are holding represents a first step in addressing the largely underserved needs of brothers and sisters of children with special needs. Based on what we have learned from three years of working with 8- to 13-year-old siblings and their parents, we hope to share with the reader special problems--and benefits--sibs often experience, the program goals that their concerns imply, and suggested activities to meet these goals.

The thoughts and activities we present in this book are not meant to be the final word in programs for siblings--sibs have been overlooked for so long, and there is still much to learn about how to best address their needs. In this handbook we offer a starting point that we hope will be expanded upon and enriched by those who use it. We hope that the book will help interested professionals better understand and address the unique concerns of these special siblings.

Chapter 1

SIBLINGS' NEEDS AND EXPERIENCES

Why Programs for Siblings?

We know that a child's disability has a significant impact on fathers as well as mothers, so it isn't surprising to learn that a disability will also affect the nonhandicapped children in the family. In A Difference in the Family, Helen Featherstone (1980) notes that "a handicap inevitably changes the experiences of each child in the family, but exceptional families offer normal children unusual opportunities as well as unusual problems" (p. 163).

The "unusual opportunities" that siblings experience have been cited by several researchers and authors who found that siblings are often well adjusted and appear to benefit from their experiences (Caldwell & Guze 1960; Lonsdale, 1978). One small study (Graliker, Fishler, & Koch, 1962) reported no adverse effects among the teenage siblings who were interviewed. Siblings of handicapped children are often characterized by greater maturity and responsibility than their age peers (Schreiber & Feeley, 1965), and show an orientation toward idealism and humanitarian interests (Cleveland & Miller, 1977). In Grossman's (1972) study, 45 percent of college-age siblings reported benefiting from having a retarded sibling; the benefits cited were an increased understanding of other people, increased tolerance, compassion, and an appreciation of their own good health and intelligence.

The opportunities provided by the handicapped sibling are not inconsequential: nevertheless, many authors and researchers (including those who cite the opportunities) are concerned about the problems that nonhandicapped siblings face. Below are some of the unusual problems that siblings of handicapped children often experience.

Overidentification. This occurs when the nonhandicapped siblings, overidentifying with their handicapped brothers or sisters, wonder whether they, like their sibling, are also defective in some way. They may ask themselves, "Am I mentally retarded too?" or "When will I start to have seizures?" Overidentification may also lead a young child to harbor fears about "catching" a sibling's disability (Seligman, 1983). Irrational as these fears may be, they can be very real, especially to young children, who often indulge in "magical" thinking.

The severity of a sibling's disability and the age difference between the siblings appear to affect the degree of overidentification. Siblings seem more likely to overidentify if the handicap is mild and especially if it is invisible (Grossman, 1972), and less likely to overidentify if the handicapped child is several years younger than the nonhandicapped child (Miller, 1974).

Embarrassment. Perhaps because of their fear that others will identify them with their handicapped sibling, nonhandicapped children are often embarrassed by their handicapped brothers and sisters. Embarrassment may be caused by questions others ask the nonhandicapped child about the sibling's handicap, or by strangers' reactions to the handicapped child (Klein, 1972). As a result, nonhandicapped siblings may be reluctant to bring their friends home (Parfit, 1975). Embarrassment may be especially keen when both the handicapped and nonhandicapped siblings are of the same sex (Grossman 1972).

Although parents may wish to spare their nonhandicapped children embarrassment associated with their handicapped child, most children go through stages when they are easily embarrassed, and these experiences may be unavoidable. Adolescents have a particularly strong need to conform. It can make a teen-ager miserable to be seen with parents, much less with a

handicapped sibling. When these feelings of embarrassment conflict with the sibling's love and loyalty to the handicapped child, the nonhandicapped sibling may experience feelings of guilt.

Guilt. Siblings who feel somehow responsible for their brother's or sister's handicap may experience irrational, but nonetheless real, guilt. They may feel that they are somehow being punished for something they said, did, or even thought near the time of the handicapped child's birth (Parfit, 1975). They may also experience a form of "survivor's guilt" about being healthy when their sibling is disabled (Trevino, 1979). A nonhandicapped child's anger at a handicapped sibling often produces guilty feelings--even when the anger is justified (Seligman, 1983).

Teasing a handicapped sibling may cause feelings of guilt, even though teasing is typical of sibling behavior (Skrtic, Summers, Brotherson, & Turnbull, 1983), and may help prepare handicapped siblings for experiences they may encounter outside of the home.

As siblings grow up, younger nonhandicapped siblings may feel guilty about surpassing their older, handicapped sibling in development or capabilities (Farber 1960). Trevino (1979) suggests that the nonhandicapped sib may drop behind in achievement in order to ease an overburdened conscience. College-age siblings, according to Grossman, may feel guilty about moving away from home and leaving their parents with the burden of care.

Isolation. Of a nonhandicapped sibling's isolation, Helen Featherstone (1980) writes:

> In dealing with the wider world of friends, classmates, and teachers, able-bodied children at times feel painfully different (p. 144).

Not only may nonhandicapped siblings miss having a brother or sister with whom they can share thoughts, experiences, and feelings, but also many sibs do not have opportunities to meet other siblings of handicapped children who may share some of the same concerns they do. This can cause siblings to feel alone with their concerns, and to feel that they are the only ones who feel the way they do.

A sibling's sense of isolation increases when the topic of the sibling's disability is treated as a taboo within the home. When the lines of communication are down within the family, the nonhandicapped sibling may experience even greater loneliness (Seligman, 1983).

Like parents, siblings enjoy opportunties to hear their own feelings described and affirmed by peers who have had similar experiences (Featherstone 1980). They also benefit from opportunities to share their own fears, hopes and doubts (Murphy, 1981). Several authors (Featherstone, 1980; Murphy, 1979; Parfit, 1975; Schreiber & Feeley, 1965) have suggested that there be groups for young siblings that give the nonhandicapped child opportunities for "catharsis, support, insight concerning relationships with family members and others, and techniques for managing various situations" (Murphy, 1979).

Need for Accurate Information. The isolation siblings experience is often complicated by their lack of information about their sibling's handicap (Seligman 1983). In the home, siblings often sense that the handicap is an uncomfortable topic for their parents to discuss. The topic may be taboo, like sex, and never discussed, or it may be discussed only in the context of problems, when emotions are tense and discomfort is high. Brothers are often even less informed about their handicapped sibling than sisters, according to one study (Cleveland & Miller, 1977). The investigators suggest that a

sister's greater involvement with the handicapped child makes her more knowledgeable about the disability. The less involved brother's lack of information may lead to anxiety about the possibility of having a retarded child of his own, the authors speculate.

Numerous authors have addressed siblings' needs for accurate, up-to-date information appropriate for the child's age. Wentworth (1974) believes that siblings want to know what caused the handicap, how severe it is, and what the prognosis is. Other authors (Parfit, 1975; Schreiber & Feeley, 1965) add that siblings need information on the genetic implications of the sibling's handicap, and the role they will play in the handicapped sibling's future.

In many ways, nonhandicapped siblings' need for information parallels parents' need for information. Featherstone (1980), however, reminds us that parents have two distinct advantages over siblings. First, being adults, parents' understanding of the world and the way it works is more mature and benefits from a longer lifetime of experiences. Second, parents have greater access to information than children do. Siblings seldom accompany parents to the doctor's office or IEP meetings and, if they do, they're unlikely to feel comfortable enough to ask questions.

The most readily available source of information for siblings is, of course, from parents, who could initiate and encourage discussion from the time of diagnosis. But because the disability often becomes a taboo or emotionally charged topic in families, Featherstone recommends that siblings have access to outside, objective sources of information. Parfit (1975) feels that books for children on handicapping conditions can be valuable, and many excellent fiction and non-fiction books on children with handicaps have been written for young readers (see Appendix of Living with a Brother or Sister with Special Needs: A Book for Sibs, Meyer, Vadasy, & Fewell, 1985; also

Appendix of Brothers and Sisters: A Special Part of Exceptional Families, Powell & Ogle, 1985).

Concerns About the Future. One very difficult topic for parents and children to discuss is the nonhandicapped sibling's concerns about the future. The handicapped child's sibling may often wonder "Will my own children be handicapped?" and "What responsibility will I have to my handicapped sibling in the event of my parent's death?" (Schreiber & Feeley, 1965).

Siblings' concerns about their childbearing potential may be rooted in their often unexpressed but nevertheless real fears about the hereditary nature of the handicap (Parfit, 1975). Often these fears are unfounded, but siblings need information and reassurance to that effect. In the event that the handicap has a hereditary basis, older siblings, prior to their marriage, need an opportunity to learn about genetic implications (Murphy, 1979).

An associated future concern is the role the nonhandicapped sibling will play in the handicapped child's future. This concern is often not addressed. Parents, perhaps unaware of their nonhandicapped child's concerns, or reluctant to confront their mortality, often fail to make adequate plans for the handicapped child's future. According to a study by McCullough (1981) of 23 middle- to upper-class families of handicapped children, 60 percent of the parents said they had not made plans for someone to care for the handicapped child if they couldn't, whereas 60 percent of the nonhandicapped siblings in the families assumed their parents had made these plans. Similarly, 68 percent of the parents had not made financial arrangements for the handicapped child's future; an equal percentage of siblings had assumed their parents had made those plans. The picture that emerges from McCullough's study is one of

parents who have not prepared for their children's future, and if they have made plans have not shared this information with their nonhandicapped children. When parents do not make adequate plans, it is easy to understand siblings' concerns. Fish and Fitzgerald's (1980) work with adolescent siblings revealed that nine out of ten siblings lacked an understanding and awareness of future plans for their handicapped brother or sister. They reported that this caused varying degrees of anxiety regarding how the handicapped child would be cared for in the future, and the sibling's role in that care.

Murphy (1979) and Parfit (1975) strongly urge that parents "openly and firmly" face the question of the handicapped child's future, perhaps with the assistance of a specialist, before the need is at hand. Unless alternative arrangements are made, responsibility for support of the disabled family member may be transferred from parents to the nonhandicapped sibling. In some families, there is a spoken and accepted agreement that siblings will one day assume this responsibility. When parents simply assume that their nonhandicapped children will take over this role, however, siblings may become resentful and may not make appropriate plans for filling the role of careprovider.

Resentment. Excessive responsibilities are one source of sibling resentment. Siblings may resent when the handicapped child is favored, overprotected, or permitted to behave in ways that are not allowed the other children in the family. Miller's (1974) study revealed that parents were much less tolerant of siblings' negative behaviors toward their retarded siblings than they were of similar sibling behaviors towards other, nonretarded siblings. Further, Miller found that nonhandicapped siblings were more likely

to be punished if they did not engage in a prescribed activity with a retarded sibling than if they avoided a similar responsibility for a nonhandicapped sibling.

Podeanu-Czehotsky's (1975) study of the families of 65 children with cerebral palsy found that in some families life was normal, whereas in other families the handicapped child was indulged in and became "a tyrant causing hidden or open conflicts among siblings."

Parfit (1975) recommends that parents avoid overprotecting the handicapped child by discussing with their nonhandicapped children behaviors that are unavoidable due to the sibling's handicap, and discipline that can help modify the handicapped child's behavior problems. Nonhandicapped siblings can advise parents of behaviors for which their handicapped siblings should be held responsible: "Children are often more sensible and sensitive about such matters than adults," Parfit claims.

Another form of resentment occurs when the nondisabled child perceives that the handicapped child is receiving more of the family's emotional or financial resources than other children in the family. In Grossman's (1972) study of siblings, 45 percent of siblings reported feelings of neglect.

Siblings, especially older daughters, may feel resentful and experience other problems as a result of increased caregiving responsibilities for the handicapped child.

Caregiving. About caregiving responsibilities, Seligman (1979) writes: "The extent to which a sibling may be held responsible for a handicapped brother or sister bears a strong relationship to the perception and feelings children, adolescents, and adults have about their handicapped sibling and their parents. Available research supports the notion that a child's

(especially a female child's) excessive responsibility for a handicapped sib is related to the development of anger, resentment and guilt, and quite possibly subsequent psychological disturbance" (p. 530).

Other authors (Farber, 1960; Fowle, 1973) note that sisters, especially oldest sisters, are more adversely affected than brothers by the presence of a handicapped child. Most authors, including Gath (1974) and Cleveland and Miller (1977) feel that oldest daughters are often pushed into a surrogate parent role with the special needs child, especially in large and low-income families. This heavy caregiving responsibility often isolates them from their age mates. If they have too many responsibilities, older sisters may be at risk for educational failure, increased disturbances (Gath, 1974), and stress (Farber, 1960). The oldest daughter in the family experiences the sibling's handicap as a double-edged sword. Cleveland and Miller's (1977) research suggests that oldest female siblings were most likely to enter helping professions, and to remain involved with the handicapped sibling as an adult; it also showed that this group was most likely to seek professional help for personal problems.

Pressure to Achieve. In families with a handicapped child, especially when there is only one other sibling, the nonhandicapped child often feels a parental pressure to achieve, as if to compensate for the "failure" of the handicapped child. Whether consciously or unconsciously, parents may pressure their nonhandicapped children to make up for the handicapped child's limitations, creating resentment and anxiety for nonhandicapped siblings (Murphy, 1979; Seligman, 1983). Grossman (1972) found this was especially true when the retarded child was a son. Older, only daughters are particularly prone to dual stresses, suggest Cleveland and Miller (1977).

These daughters feel pressured to make up for the parents' unfulfilled hopes for the handicapped sibling; they also experience the increased parent-surrogate responsibilities that are most often delegated to daughters rather than sons.

Summary

Clearly, siblings of children with special needs are an at-risk population. However, siblings' needs, like fathers' needs, have been overlooked by policies that focus solely on the handicapped child or the child's mother. It appears appropriate to provide siblings with opportunities to address concerns cited in the research literature. Further, parents, who are often unaware of the extent and range of sibling concerns, should be provided with opportunities to become more informed about the needs of their nonhandicapped children.

Finally, these opportunities should be provided when the sibling is young, before the concerns become major and highly sensitive problems. Waiting until problems develop runs many risks. As Mandlebaum and Wheeler (1960) have noted, "Efforts to call attention to the neglected needs of other siblings usually aroused anger and resentment." Gayton (1975) encouraged "anticipatory guidance" for siblings. By taking a proactive approach with young siblings of handicapped children and their parents, it is possible to help minimize siblings' "unusual problems," and maximize their "unusual opportunities."

Chapter 2

SIBSHOPS FOR SPECIAL SIBLINGS

In the following sections, we suggest how you can conduct "Sibshops" for brothers and sisters, ages 8 to 13, of children with special needs. Sibshops are meetings or workshops planned with the particular needs of young siblings in mind. A sibshop may be a 2 to 3-hour meeting on a Saturday morning, or a 2-day overnight camping trip. It may include a panel discussion with other siblings or parents, or a trip to a local group home for adults. What sibshops have in common is the inclusion of an informational component and a recreational/social component. Information may be provided through a group discussion format or through a panel presentation. The recreation may consist of a cookout, a volleyball game, or an ice-cream making session. We suggest activities that we have found successful in sibshops we have offered, and we encourage our readers to try their own ideas. Some Sibshops have activities for parents, too.

Sibshop Goals

Each activity area we discuss below is designed to reflect sibling concerns that we became aware of in the research we reviewed, and in our pilot work at the University of Washington's Experimental Education Unit. The activities we designed and chose help accomplish the following program goals:

Goal 1. To provide siblings with an opportunity to meet other siblings in a relaxed, recreational setting.

The chance to meet other sibs in a casual atmosphere and join them in recreational activities has several benefits for participants. First, it can help reduce a sibling's sense of isolation. Siblings in these programs quickly learn that there are others who experience the special joys and challenges that they do. Second, the casual atmosphere and recreational activities promote informal sharing and friendships among participants. Friendships begun at Sibshops and continued outside of the program offer sibs ongoing sources of support.

Third, the recreational setting of the Sibshops helps assure that they will be rewarding for the child to attend. If a sibling regards a Sibshop as yet another time demand associated with the handicapped child, he or she may find it hard to be receptive to the information presented in the workshop. Further, if the sibshops fail to offer anything that is personally satisfying for the sibling, he or she is unlikely to attend them in the future. Parents tell us that sibs are sometimes reluctant to attend their first SIBSHOP, but are often eager to attend subsequent meetings.

Goal 2. To provide siblings with an opportunity to discuss common joys and concerns with other siblings; and

Goal 3. To provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of handicapped children.

Sibs routinely face problems that are not experienced by other children. Defending a brother or sister from name-calling; responding to questions from friends and strangers; and coping with a lack of attention or exceedingly high expectations from parents are only a few of the problems siblings experience. At a Sibshop, participants discuss their

common concerns, interests, and joys, and thereby decrease the sense that they are alone with their experiences. Further, Sibshop participants have opportunities to compare how others have handled difficult situations. This experience can offer siblings a broad array of solutions from which they may choose.

Goal 4. To provide siblings with an opportunity to learn more about the implications of their brothers' or sisters' handicaps.

As we reviewed earlier, the research literature strongly suggests that one of siblings' greatest needs is for information about their brothers' or sisters' handicapping conditions. Sibshops offer participants opportunities to learn about the effect the disability may have on the special child's life, schooling, and future.

Goal 5. To provide parents with an opportunity to learn about common sibling concerns.

Because parents are often unaware of sibling concerns, some Sibshop activities attempt to help parents better understand "life as a sib." These activities allow parents to meet with a panel of adult siblings and learn about the joys and challenges of growing up with a special brother or sister. Parents learn what other siblings appreciate in their parents' treatment of children, and what they wish their parents had done differently.

Chapter 3

SIBSHOP DISCUSSION ACTIVITIES

Below we describe discussion, informational, and recreational activities that we have found successful in reaching these Sibshop goals. We offer them as suggestions, a starting point that you can expand upon and adapt to the needs of the siblings you serve.

These activities are designed to help meet two Sibshop goals for siblings:

- To provide an opportunity to discuss common joys and concerns with other siblings;
- To provide an opportunity to learn how others handle situations commonly experienced by siblings of handicapped children.

Some Sibshops also have one goal for parents:

- To provide an opportunity to learn about common sibling concerns.

Sibling discussion activities are designed to allow siblings--perhaps for the first time--a chance to discuss their lives with other people who share similar experiences. The activities are not a form of group therapy, nor are they an adequate substitute for a child who needs more intensive counseling, although they can be "therapeutic" for some siblings.

Below, we suggest three discussion activities, "Dear Aunt Blabby," Sibscenes, and a facilitated group discussion. All three activities encourage siblings to share their experiences, but they differ in the levels of introspection they require from participants. In "Dear Aunt Blabby," participants share their experiences as they offer advice to a hypothetical

letter writer. In Sibscenes, participants discuss their lives as they respond to a fictional sib's experience in a story. These two discussion activities allow the siblings to talk about sib concerns without necessarily having to reveal their personal experiences. The facilitated group discussion permits a direct discussion of the participants' lives and experiences. Often, it is more comfortable for siblings if they are given opportunities to indirectly discuss their personal experiences; this is especially true with younger siblings, or with groups that are just getting to know each other. Then, as the children become more comfortable with others in the group, they may wish to talk more directly about their personal experiences.

Dear Aunt Blabby

The vehicle for this discussion activity is Aunt Blabby, an advice columnist who answers letters from sibs with concerns similar to those the participants may experience. You, as the group facilitator, read a letter to the participants and ask them, as "experts" on the subject of being a sib, how they would respond. Sibs then help "Aunt Blabby" advise the letter writer, drawing on their own experiences. Siblings may not have profound advice to offer, but they will have experiences to share that are similar to the letter writer's experience. The exercise helps participants learn that others have faced problems like theirs, and that there are a variety of possible solutions. As a facilitator, you will want to accept each participant's solution to the problem, but reinforce those that are especially helpful.

Below is a sample of letters you may wish to draw from for a "Dear Aunt Blabby" activity. You may wish to place them in envelopes and allow a participant to draw one from a pillowcase or other "mailbag" or box. "Dear Aunt Blabby" and other discussion activities seem to work best in groups of 5

to 7. A group of this size encourages a variety of responses, yet allows each participant a chance to talk. Although it's good to have 6 to 7 letters in reserve, plan on responding to only 3 or 4 letters per session. To keep the interest level high, be sure to quit before participants become bored.

Dear Aunt Blabby,

Sometimes I feel like the invisible man. My brother has Down syndrome and has a lot of needs that seem to take up all my parents' time. It seems that the only time they pay attention to me is when I get into trouble, and that's no good. How do I let them know that they have two kids instead of one?

The Invisible Man

Dear Aunt Blabby,

Maybe you can help me with my problem. My sister, who is three years older than I, is retarded. Sometimes, my friends ask me what's the matter with her and how she got that way. Once my teacher even asked. I usually get red in the face, shrug my shoulders, and say, "I don't know." I never know what to say. Any suggestions?

Speechless

Dear Aunt Blabby,

Boy am I mad! For the fifth time tonight my sister has bugged me while I've been trying to do my homework. She is always bugging me! Especially when my friends come over. Help!

Fuming

Dear Aunt Blabby,

I have a problem that I'm sort of ashamed of. My brother, who has cerebral palsy, embarrasses me. Don't get me wrong--in a lot of ways he's a neat guy. He can really do a lot for himself, considering his handicap. My problem is that I get embarrassed when people stare at him in the shopping mall, or when he drools. What can I do about this problem?

Embarrassed

Dear Aunt Blabby,

I hope you can help. People sometimes ask me how my brother became handicapped. I'd tell them, except I don't really know! My parents have never explained it to me very well, and I feel funny asking them. Can you give me some suggestions on how to ask my parents questions about my brother's handicap?

Need to Know

Dear Aunt Blabby,

Maybe you can help me. I really like my sister. She has a lot of special needs, but I love her a lot. My problem is that I get bored just going for walks and watching TV with her. What other things can I do with her that both of us would find interesting?

Curious

Dear Aunt Blabby,

I have a problem that maybe you can help me with. Just because my brother is developmentally delayed and I'm not, my parents expect me to be

some sort of "Superkid," and get perfect grades in school. Does that seem fair to you? What can I do?

I'm no Superkid

Dear Aunt Blabby,

Is it OK to tease your handicapped sister? I mean, I tease my other brothers and sisters, but when I tease my handicapped sister, I sometimes feel bad. I'm not doing it to be mean or anything--it's just teasing. Is it OK or not?

Feeling Guilty

Dear Aunt Blabby,

I don't know what to do. My brother, who is a year younger than I and is retarded, just started going to the same school as I do. My friends make fun of the special education kids, and I have even heard them call my brother names and laugh at the things he does. Aunt Blabby, what can I do?

Perplexed

Dear Aunt Blabby,

When I get angry at my brother, who has autism, my parents yell at me and tell me that I shouldn't get angry with him because he has autism. Then I feel bad. It doesn't seem fair. I thought we were supposed to treat him like anyone else.

I Don't Get It

Sibscenes

These are very short stories that focus on feelings that sibs may experience. Examples of embarrassment and anger as well as pride and understanding are presented in vignettes that siblings choose and facilitators read for discussion. You may wish to place each Sibscene in an envelope and type the titles (e.g., Sibscene: Friends--Melissa's Story) on the outside of the envelope, and allow participants to select an envelope for you to read.

Following each Sibscene are questions that facilitators can use to guide discussion. They have been adapted from a book we wrote for siblings called Living with a Brother or Sister with Special Needs: A Book for Sibs (Meyer, Vadasy, & Fewell, 1985). Like the "Dear Aunt Blabby" activity, Sibscenes encourage participants to share experiences and solutions to problems they have encountered. To facilitate discussion, remember to use open-ended questions, such as ones that begin with "why," "what," or "how." Again, as a facilitator, you will want to acknowledge all responses, but reinforce those that are appropriate, innovative, and practical.

Sibscene: Friends

Kevin's Story

Kevin was so angry he wanted to kick something, or better yet, someone. He and his friends had just finished their basketball practice when a group of wheelchair athletes came into the gym to play basketball. Kevin and his teammates watched the athletes roll their wheelchairs on the court and begin to play. Then one of Kevin's teammates yelled, loud enough for everyone to hear, "Hire the handicapped! They're fun to watch!" Some of the other kids laughed. Kevin, whose brother has

cerebral palsy, said nothing. All that night and the next day he had a knot in his stomach.

Questions

1. Why was Kevin upset?
2. What could Kevin have said to his friends?
3. Why do people sometimes laugh at people with handicaps?

Sibscene: Friends

Chen's Story

Chen wishes people would understand that he and his sister are not the same. Both Chen and his twin sister Helen go to the same school. Chen is in the sixth grade, and Helen is in a class for children who have special learning problems. Although Helen tries, she has a hard time reading anything more difficult than a book for second graders.

At recess or after school, Chen and his friends sometimes tease each other. That's usually OK except when they call Chen a "retard" because of his sister. He hates it, but he tries to ignore it, because he knows that if he gets mad, his friends will tease him even more.

Questions

1. Why was Chen upset?
2. Has anyone ever thought you were handicapped because your sib is?
3. What should Chen do?

Sibscene: Friends

Melissa's Story

Melissa hates to bring her girlfriends home. Kelly, her older sister, is retarded, and doesn't have any friends in the neighborhood. So whenever Melissa brings friends home to play, Kelly barges in. Kelly always wants Melissa's friends to play with her stupid little dolls. Melissa's friends are usually polite to Kelly, although a few of them will look at each other and snicker when Kelly starts up. Then Melissa gets red in the face and sometimes wishes Kelly would take a long walk and not come back.

Questions

1. Why do you think Kelly bothers Melissa when she has company?
2. What could Kelly do so Melissa doesn't bother her and her friends?
3. Do you ever have problems when your friends come over? What do you do?

Sibscene: Unselfishness

Jerome's Story

Even though she's severely retarded and can't see, Bonita's a lucky little girl. She has an older brother, Jerome, who's crazy about her. He puts her in her stroller and takes her out for walks, and sometimes sings her songs, which makes her smile and laugh. More than once, he's even changed her dirty diapers. Some of Jerome's friends wonder why he spends

time helping a sister who can't see or walk or play games. One of his friends actually asked him why he did it. Jerome replied, "Because I know if I was retarded and Bonita wasn't, she'd do the same thing for me."

Questions

1. Why is Bonita a "lucky little girl?"
2. How does Jerome take care of her?
3. The title of this Sibscene is "Unselfishness." What does it mean to be "unselfish?"
4. What are some ways in which you are unselfish to your special sib?

Sibscene: Anger

Sarah's Story

For over a week, Sarah had worked on a 10-page report for school on the history of her state. On Sunday night, after she finished the report, her brother Mike decided to color her report with a crayon. Mike is mentally retarded. Sarah caught him and was furious. She screamed at Mike and told him never to touch her homework again. Mike didn't understand why Sarah was yelling at him, and he began to cry. That made Sarah feel bad. She wanted to teach Mike a lesson because she had put a lot of work into her report. She was disappointed and discouraged when Mike wrecked it.

Questions

1. What has your sib done that has made you angry?
2. What did you do when you were angry? Did it help?

3. What are some good things to do with your anger?
4. How can you prevent situations that make you angry at your sib?

Sibscene: Accepting Differences

Robin's Story

When Robin and her friends returned to school last year, there were a lot of changes. Not only were there five new Vietnamese students, but there were two new classes for kids who are handicapped. One day at recess, Robin's friend Anne said, "I don't know what's happening to our school. With these refugees and the weirdos in the special classes, school's just not the same."

Robin was surprised at what Anne had said. Robin's older brother Bill has Down syndrome. When he was younger and was going to school, he had to take a bus to a school that was far away from everyone else. Robin likes the idea of all kinds of kids going to school together now.

Questions

1. Why did Anne have a harder time than Robin accepting handicapped kids in her school?
2. How can we make it easier for people to accept other people's handicaps?

Sibscene: Guilt

Joel's Story

"Supper's almost ready," Joel's mother announced as Joel was watching TV. "Will you go down the block and tell Benjamin it's time to come home?"

Humph, Joel thought as he left the house, why do I always have to go get that kid in the middle of my very favorite TV show?

Joel yelled impatiently for his brother as he walked down the block. Joel thought about how his retarded brother was always screwing up his life. "Benjamin! It's time for supper!" He continued yelling for Benjamin all the way down the block until he reached the corner. There was Benjamin, playing kickball with kids a lot younger than he was.

"Benjamin, you idiot!" Joel roared. "Didn't you hear me calling you? Boy are you stupid!"

Benjamin looked down at the ground and his lower lip began to tremble. He was about to cry. Walking home, both boys were quiet.

Benjamin was upset that his big brother had yelled at him. Joel felt rotten because he had called his little retarded brother a stupid idiot. Benjamin didn't need to be reminded that he was slow. He already knew that.

Questions

1. What does guilt mean?
2. Why did Joel feel guilty?
3. Should Joel feel guilty?
4. Can guilt ever help us?
5. Do you think it helped Joel?

Sibscene: Guilt

Vanessa's Story

"Dear diary," wrote Vanessa. "I have a terrible secret that I have never shared with anyone. Before my brother Christopher was born, I was the youngest in our family. I got a lot of attention from my folks and my brothers and sisters. When I was four, my mom told me we were going to have a new baby in the family. I wasn't too happy about that news. Just before Christopher was born, I had a temper tantrum and my mom got real upset at me. Two days later, my mom had Christopher. I remember that he couldn't come home from the hospital right away because something was wrong. Chris is now eight years old. He acts very strange. He can't read, and the few words he can say usually don't make sense. Dear diary, my terrible secret is that I think Chris's problems are all my fault."

Questions

1. Why does Vanessa feel guilty?
2. Are her brother's problems her fault?
3. Should Vanessa feel guilty?
4. What could Vanessa do to feel less guilty?

Sibscene: Jealousy

Emma's Story

Emma thought to herself, I know this sounds crazy, but sometimes I wish I had cerebral palsy! Lately Emma has been feeling jealous of her sister, Amy, who has cerebral palsy. It seems to Emma that Amy gets all

the attention. Emma's soccer games never seem as important to her parents as meetings at Amy's school or at the cerebral palsy center. If Emma brings home a paper with a B minus grade, her parents say, "Well, you'll have to try harder next time," although they make a big fuss about anything Amy brings home, no matter how sloppy it is. When Amy was the state cerebral palsy poster child, Emma had to stay with her aunt while Amy got to meet the governor at the TV station. It's just not fair, Emma thought.

Questions

1. Why was Emma jealous of Amy?
2. Have you ever been jealous of the attention your special sib gets?
3. How can you let your parents know that you need attention too?

Sibscene: Overinvolvement

Marty's Story

To most adults, Marty probably sounds like the perfect son. Every day after school, he comes straight home to take care of his brother Paul, who has spina bifida, so his mom can go shopping and run errands. Marty will play games with Paul, fix him a snack, take Paul for a walk, help him with his schoolwork, or even give Paul a bath. However, while Marty is doing all these things, there are a lot of things he isn't doing. Marty isn't in the school play, he isn't playing football, he isn't hanging out with his friends, he isn't learning to play the guitar, he isn't reading books. Marty, you might say, is overinvolved with his brother Paul.

Questions

1. What does it mean to be "overinvolved"?
2. How do you know if you're doing too much for your special sib?
3. What could Marty do to have more time for himself?

Sibscene: Embarrassment

Michelle's Story

Only an hour ago Michelle couldn't wait to go shopping for school clothes at the mall. Then her mother told her that her handicapped sister, Jenny, would be coming too. Now she dreaded the idea.

She thought to herself, this is just what I need. Michelle had just started junior high. What would happen if the kids from her new school saw her at the mall with Jenny? And that awful wheelchair? And her drooling? And the way she bites her hand? It wasn't that Michelle didn't love Jenny, but she hadn't forgotten other times when Jenny had embarrassed her. Like the noises she once made during the quiet part of the band concert that Michelle had played in. Or the puddle Jenny made last Easter when she peed in her wheelchair, right outside of church.

Questions

1. Has your sibling ever embarrassed you?
2. What have you done?
3. What are some good ways of handling embarrassment?

Sibscene: Pride

Mike's Story

"C'mon Tony! C'mon Tony!" shouted Charlie and Mike from the stands at the Special Olympics. On the field was their brother Tony, who is mentally retarded. Tony is short and round, but he was biting his lip and swinging his arms as he raced toward the finish line.

"Yay! All right! Wa-hooie!" screamed Charlie and Mike as Tony crossed the finish line in second place. As soon as Tony stopped, he pushed up his glasses on his nose, looked up at his brothers in the stands, smiled, and flashed a "V for victory" sign with his fingers.

On their way down to the field to congratulate him, Mike thought about what a neat kid Tony is. Sure, he could be a royal pain sometimes, but look what he did today! He couldn't remember ever being so proud of his little brother.

Questions

1. What has your sib done that you have been proud of?
2. How do you let your sib know that you are proud of him?

Sibscene: Maturity

Kerri's Story

One evening Kerri was in her room getting ready to go to the movies with her friends. Her parents were also going out. It was their anniversary and last week Kerri's mom bought a new dress to wear to dinner.

Kerri heard the phone ring and her mom answered it. Mrs. Randle, the baby-sitter, was calling to say that her daughter just started coming down with the flu and she couldn't come tonight to take care of Lee.

Kerri bit her lip. Lee, her brother, has epilepsy, like one of Mrs. Randle's children. Kerri's parents never worried when Mrs. Randle baby-sat for Lee. Ever since she started junior high, Kerri's parents really tried to get a baby-sitter for Lee on weekends so Kerri could go out with her friends.

Kerri heard her dad say he would have to call the restaurant and cancel their reservation for dinner. She came out of her room and said, "You and mom get your coats on or you'll be late. I'll stay and watch TV with Lee."

Kerri's mom gave her a big hug. The look of pride her dad gave her made her feel very grown up.

Questions

1. What does "maturity" mean?
2. How did Kerri act mature?
3. Are sibs of handicapped children more mature than other kids their age? (If yes, why?).

Sibscene: Worry

Allen's Story

Last month Allen's parents told him the bad news: Allen's new little brother has Down syndrome. "He'll be just like us in almost every way,"

his mother told him, "except it will take him longer to learn. The doctor said that he'll probably be mentally retarded."

This year Allen's been having a terrible time in math. He's almost flunked his last two tests. Today when he had a hard time again on his math test, Allen wondered: Am I retarded too?

Questions

1. Why did Allen wonder if he was retarded?
2. Have you ever worried that you might have the same problem as your sibling, or that you might get it in the future?
3. What could Allen do so he wouldn't have to worry?

Sibscene: Worry

Joan's Story

Joan went with her family to an Association for Retarded Citizens family picnic last summer. At the picnic, Joan saw many handicapped adults. It made her think about her brother, who is retarded and has a heart problem: Will he live to grow up and go to school and get married? Or will his handicap get so bad that he dies?

The next week, at her cousin's wedding, Joan started thinking about her own future. Like her cousin, she wanted to get married and have children someday. Still, she wondered: If I have children, will they be retarded like my brother?

Questions

1. Do you ever wonder about what will happen to your special brother or sister in the future?
2. What do you think will happen to your sib when he or she grows up?
3. Who can you talk to when you wonder about your and your sib's future?

Sibscene: Loneliness

Jason's Story

When kids in his class start talking about their brothers or sisters, Jason gets very quiet. He doesn't say much about his special sister, Erin. What would he say? Who would understand?

Suppose one girl bragged about how her brother won a prize at a Science Fair. What would Jason say? How proud he is that Erin, who is ten, can finally go to the bathroom by herself? Jason is proud of Erin all right, but they wouldn't understand.

If a classmate complained how her sister is always getting into her things, what could Jason say? That his father had to put a lock on his door to keep Erin out, because Erin doesn't know any better? Once she completely wrecked a model spaceship he had almost finished. No, his friends wouldn't understand.

Just once, Jason thought, I'd like to meet another kid who has a sister like Erin.

Questions

1. Why was Jason feeling lonely?
2. What could Jason do to feel less lonely?
3. Does it help to know other sibs with handicapped brothers or sisters? Why?

Open Discussions

Open group discussions may be used successfully with older sibs or with articulate younger siblings who do not require the structure of the "Dear Aunt Blabby" or Sibscene activities to talk about their lives. They may also be valuable for sibs who have previously participated in "Dear Aunt Blabby" or Sibscene activities and are ready to participate in a more in-depth or personal discussion.

Open discussions follow a facilitated group discussion format. Although participants select the topics for discussion, the discussion is not without structure. Facilitators introduce the activity, establish a few ground rules, probe for topics of interest or concern, and facilitate and close discussion when appropriate.

Below is an example of how one facilitator introduced a discussion and established ground rules. It was adapted from an article by Ken Moses (1982) on a sibling conference he offered for high-school age brothers and sisters:

> All of you are different from each other in hundreds of ways: What you like to eat, the way you look, the clothes you choose, and so on. But there is an important way that you are the same: you are all brothers or sisters of children who have special needs.

As special educators we've learned a lot about handicapped kids, but very little about their brothers or sisters. We don't know whether having a special sib is a good thing, a bad thing, or a little of both.

Today we'll have a chance to switch roles. In a way, you'll be the teachers and I'll be the student, although we'll all be learning from one another. We'll have a chance to learn what you think and how you feel about your special sib, your parents, your family, your friends, and yourself.

There are a few rules. First, I'd like you to talk about yourself and how you feel rather than guess how others feel. Second, I'd like you to feel free to disagree with one another and me. If someone says something that doesn't ring true to you, speak up! Third, I'd like us to maintain confidentiality. That usually means not telling anyone outside of the group what was said inside the group. I'd like it to mean that we are kind to one another. That means not laughing when someone shares something personal. It also means that when we talk about what we say outside the group, we protect one another and not use names.

Now, I'd like you to introduce yourself, and tell us what brings you here today. If there is something you'd like the group to talk about, please mention it.

Going around the circle, sibs introduce themselves and share why they came. Facilitators will wish to acknowledge and accept all responses, including the inevitable, "My mother made me come." As sibs introduce themselves, facilitators may ask a question or make a comment. Throughout the

introductions, sibs may need to be reminded that they can ask each other questions, make comments, or suggest topics for discussion.

When a sibling offers a problem or topic for discussion, the facilitator will want to find out if it is a concern that is shared by other sibs. The facilitator may wish to "check in" with the other sibs and ask, "I wonder if other sibs have ever experienced anything like this." This will not only give the facilitator an idea of how widespread the concern is, it will also make the participants reflect on their lives and think about their common experiences. The facilitator should list the topics the siblings suggest and note how many siblings indicate interest in each topic.

Look over the topics the siblings mention (we recommend that you write them down), and select a topic for discussion. The topic you choose will depend on the siblings' relative interest in the topic and its appropriateness for discussion. Some topics may not be appropriate--they may be too specific for general discussion. Some topics may be requests for specific information. Of course, you shouldn't ignore these topics or questions, but try to address them individually.

To begin discussion, ask the sib who suggested the chosen topic to share some further thoughts on the subject, and then open it up to the group for discussion. For instance, if the siblings want to talk about what to do when strangers stare at their sib, the facilitator may wish to guide the discussion to elicit a wide range of problem-solving strategies for responding to people's stares. Below is an example of questions that can be used to facilitate a group discussion of effective strategies. Remember to use questions that begin with "what," "why," and "how," because those are most likely to elicit discussion.

Step 1. What's the problem? Ask the sib who brought up the topic to expand on it. For example: "Shannon, tell us some more about what happens when people stare at your sib."

Step 2. Who else has the problem? You probably know from the siblings' introductions who else has experienced this problem. Present the concern to the group. For example: "Other people said that people sometimes stare at their sibs. I'm interested: What happens to the rest of you?"

Step 3. Why does the problem exist? This can help the group explore the issues underlying the problem. For example: "Why do you think people stare at people who are handicapped? Why does this bother you?"

Step 4. What have you tried? This will help draw out the array of strategies participants have used. "What do you do when people stare at your sib?" The facilitator will wish to acknowledge all responses but give special attention to those that are appropriate, creative, or workable.

Step 5. Has it worked? An important followup question to Step 4. For example: "What happens when you do that or say that?"

Step 6. What are some other ways of solving this problem? Drawing on what the group has learned in Step 3 (why does the problem exist) and the strategies that worked in Step 4 (what have you tried), the group, under the facilitator's guidance, searches for additional creative solutions. "A moment ago we said that people who stared at handicapped children did so because they probably don't know any handicapped people. What are some other ways that we can help people get to know people with

handicaps so they won't stare at them?" (A most creative solution to this problem was volunteered by a sib whose mother says to staring strangers: "You seem to be interested in my daughter. Would you like to meet her?")

Remember that these are only guidelines for group problem solving; not all discussions will follow this outline exactly. Also, discussion may not always focus on problems sibs experience. Participants may also wish to express their thoughts and opinions on a wide variety of subjects related to their experiences as siblings of a child with special needs.

Chapter 4

PARENT DISCUSSION ACTIVITIES

It has been our experience that parents appreciate an opportunity to learn about common sibling concerns. These concerns are often difficult for parents to discuss with their own children. We have found that a sibling panel, comprised of late teen, young adult, and adult-aged siblings of persons with special needs can provide a valuable perspective of the joys and concerns that sibs experience.

Sibling panels are relatively easy to run, considering the value of information exchanged. Here are a few guidelines to help insure that your sibling panel is as productive as possible:

1. Balance the panel in terms of age, sex, and disability of sibling.
2. Sibling panel members who are close in age or younger than the handicapped person will have a better perspective than siblings who are considerably older than their handicapped brother or sister.
3. In order to insure candor, "disinvite" the siblings' parents and handicapped brothers or sisters.
4. In smaller communities, where families know each other, panel members may not feel comfortable discussing their experiences. In this case you may want to "import" sib panel members from other communities, or, at the very least, make provisions for confidentiality.

At the workshop, before introducing the panel members, welcome the parents and panel and note the workshop's goal: To provide parents with an

opportunity to learn about common sibling concerns and, in general, life as a sib. Ask the parents to briefly introduce themselves and their families.

The sibling panel may then introduce themselves and share information about themselves, their special sib, and their families. The following is an outline of topics the panel could address. An outline like this should be sent to the panel members prior to the meeting so that they are prepared to talk about specific concerns.

Greetings! Thank you for agreeing to be a member of a sibling panel. At the workshop, you'll be asked to tell us something about:

1. Yourself (age, occupation or school status, where you live, special interests or activities, when you learned of your sibling's handicap, and how was it explained).
2. Your handicapped brother or sister (age, school status or occupation, disability, interests, positive and negative qualities).
3. Aspects of having a handicapped sibling that you have found enriching.
4. Aspects of having a handicapped sibling that you have found discouraging or distressing.
5. Any other anecdotes about your brother or sister and/or your family that you would like to share.

Following the introductions, the parents have an opportunity to ask the panel members questions. Questions and discussion among parents and panel members will be the most valuable portion of the workshop, and an ample amount of time should be left for it. As parents' concerns surface, the facilitator

may wish to encourage panel members and other parents to share how their families attempted to minimize a similar sibling concern.

At the end of the workshop, the facilitator may wish to bring closure by asking each panel member to respond to two questions:

1. In retrospect, and in regards to raising a family with a handicapped child, what do you think your parents did especially well?
2. And, what do you wish they had done differently?

Chapter 5

INFORMATION ACTIVITIES

These activities are designed to help achieve the following Sibshop goal:

- To provide siblings with an opportunity to learn more about the implications of their sibling's handicap.

As we reviewed earlier, numerous authors, researchers, and siblings themselves have noted that brothers and sisters of handicapped children have a great need for information about their siblings' handicaps and the implications of the handicaps. Their need for information parallels parents' needs, although they have far fewer opportunities to obtain information. Ideally the information siblings need is available from their parents; however, because the handicap is an uncomfortable topic in many families, parents are often reluctant to discuss it, and consequently many siblings' questions go unasked.

Sibs not only need to have the disability and its implications explained to them once or twice, but also, because of their changing needs, they will need to have the subject reinterpreted as they grow. (Obviously, this need is best addressed when parents and child enjoy open lines of communication, and when the disability remains an open topic in the family. One goal of the Sibshop parents' discussion is to help parents become aware of sibs' needs for information, and the importance of communication between parent and child.)

Several authors (Featherstone, 1980; Parfit, 1975) have suggested that siblings could benefit from objective sources of information. Books, such as

Living With a Brother or Sister With Special Needs (Meyer, Vadasy, Fewell, 1985) can provide siblings with information about specific handicapping conditions, treatments, future concerns, and emotions they may experience.

Sibshops, to a limited extent, can provide participants with an opportunity to learn about their sibs' handicaps and the implications of the handicaps. A group setting is more useful in conveying general rather than specific information. For instance, a discussion of the causes of Down syndrome will have limited interest unless all the participants have siblings with Down syndrome. You should keep in mind the interests of all participants, when you plan discussions, and in this case, a better focus would be a discussion on mental retardation. Below are some topics you may wish to focus on when addressing siblings' informational needs.

School Programs for Children with Special Needs

Many siblings have handicapped brothers and sisters who receive the services of physical or occupational therapists, speech therapists, and special education teachers, yet few may really know what these professionals do with their special sibs on a daily basis. Consider asking a speech therapist, an occupational or physical therapist, and a special education teacher to briefly explain what they do with kids with special problems. Demonstrations are especially recommended. Be sure to leave ample time for questions.

The Future

As the research literature suggests, sibs often have unasked questions about the future. Questions about the future that can be addressed at a Sibshop are: What will happen to my sib when she grows up? Will my sib live with me someday? To lead an informational discussion on these topics, the facilitator will either need to be aware of the range of housing and vocational services available for adults, or will need to invite representatives from a group home (or other residential facility) and a sheltered workshop (or other vocational programs) to present information to participants. Perhaps the best alternative is to sponsor a field trip to residential facilities and to businesses that employ people with handicaps. The chapter on the future in Living With a Brother or Sister With Special Needs can provide you with background information to help answer these questions.

Parents of Handicapped Children

Because they have been protected by their parents, many siblings have never heard parents honestly discuss the impact of their child's disability, and the special problems and rewards parents face. Sibs who have an opportunity hear parents discuss their families can better understand parent concerns and their own families.

When you invite two or three parents to share their families' stories and answer sibs' questions, make sure that the parents you invite have more than one child and are not parents of Sibshop participants. Topics the parents could briefly address are: the family's reaction to the diagnosis; special

joys and concerns they have for their special child and family; and the effect the child has had on the family, especially the nonhandicapped children. Children often find it easier to talk to other children's parents, so be sure to leave plenty of time for questions.

Older Siblings of Handicapped People

Sibshop participants often find it very instructive to hear the experiences of adult siblings of handicapped people. Invite a small panel of older sibs to discuss their lives, experiences, families, problems, and solutions. The outline for the sibling panel provided above under Parent Discussion Activities can be easily adapted for this purpose.

food, hobby, and TV show) but not their names. The papers are collected and redistributed. Participants then must find the person who wrote on their piece of paper by asking other sibs what their favorites are (e.g., "Is your favorite TV show Magnum P.I.?"). Because participants are simultaneously seeking their partners and being sought, the activity creates mild confusion, but don't worry--it's a pleasant, constructive commotion. Once everyone finds his or her partner, sibs introduce the person they found and that person's favorites.

Interviews. For another introductory activity you can ask participants to find a partner (preferably someone they haven't met before) and try to find out as many things as possible about their new friend (or if they already know each other, new things about their old friend) in five minutes. At the end of the time, participants introduce the person they "interviewed."

Draw-a-picture. In the draw-a-picture activity, sibs are handed a piece of paper that contains two small boxes. Sibs are instructed to draw two simple pictures, but no words, that tell something about themselves. Sibs then hand their papers to their partners. The partner uses the picture to introduce the sibling in a humorous way. Facilitators can be good role models, poking fun at each other in a good-natured way. For instance, if you are handed a paper that has drawings of a person running (to indicate a favorite hobby) and the number 11 (to indicate age) you could introduce the person this way, "This is Greg. He's running--from the law. The 11 stands for how many years he's been running from the law, and the number of states he's wanted in." Greg, of course, will protest

and can announce what the drawings are really supposed to represent. Greg of course, then gets a chance to introduce you.

Strengths and Weaknesses. Strengths and weaknesses interviews take the introduction activities one step further: they help sibs begin thinking in terms of their special sib. This activity serves three purposes: first, to introduce the participants; second, to acknowledge that everyone has strengths and weaknesses; and third, to give siblings permission to say something unflattering about their special sib. Each person is handed a sheet of paper that says:

> "Everybody has strengths--that is, things they do well. Everybody has weaknesses--things they don't do so well.
>
> Turn to the person next to you, interview him or her, and find out one strength and one weakness. Also, find out one strength and one weakness about their handicapped brother or sister.
>
> Name of person you interviewed _____
>
> One strength _____
>
> One weakness _____
>
> Name person's handicapped brother or sister _____
>
> Their strength _____
>
> Their weakness _____."

In introducing the activity, you can model the sharing you would like to see from the sibling. If you are a lousy singer but a good cook, describe in some detail how bad and good you are at these activities. Siblings then go around the circle and introduce their partners, talking about their strengths and weaknesses and their sibling's characteristics.

Games

Indoor or outdoor physical games are an excellent means of developing a group identity, breaking the social ice, and dissipating excess energy, especially after group discussions or informational activities. They are also good warm-up activities at the very beginning of the program, as participants trickle in.

Besides basketball, volleyball, and flag football, we have had great fun with the so-called "new games." New games are largely cooperative, slightly offbeat, and undeniably fun activities that can be enjoyed by children of many different ages and ability levels.

We highly recommend the following books of games. Many can be found in public libraries:

New Games Book, Andrew Fluegelman, Garden City, N.J.: Headlands Press, Inc., Doubleday & Co., 1976.

More New Games and Playful Ideas from the New Games Foundation, Andrew Fluegelman, Garden City, N.J.: Headlands Press Inc., Doubleday & Co., 1981. (This book gives good ideas on presenting games.)

The Cooperative Sports and Games Book: Challenge Without Competition, Terry Orlick, N.Y.: Pantheon, 1978.

Everybody Wins, Jeffrey Sobel, N.Y.: Walker and Co., 1983.

Food Activities

Our sibs have been crazy about food activities. These are opportunities to cooperatively cook and partake in a new or favorite food. These activities

have revealed siblings' enthusiasm for even the less glamorous chores, like pot scrubbing, which has amazed to us and shocked their parents.

If you've never organized a group cooking activity, here are a few thoughts to keep in mind:

1. Be prepared. Set up your materials before participants arrive.
2. Identify jobs for as many siblings as possible. We have found that sibs would rather be doing something than watching. When you plan the activity, consider the number of hands you will want to keep busy.
3. Keep it simple. If you can't remember back that far, kids can be picky eaters. We learned that about 50% of siblings thought that tomatoes (much less green peppers!) were "too weird" on nachos. Ditto for mushrooms in spaghetti sauce. That doesn't mean you can't have some on hand for adults and kids who like them, but don't assume everyone will want them.
4. Think about how much time you will need for the project. Select or adapt projects to accommodate for available time.

Below are some food activities that we've enjoyed:

Super nachos. Jobs here are grating cheese, chopping tomatoes and green peppers, spreading tortilla chips, and assembling the dish before running the nachos under the broiler. Good project when time is limited.

Cream puffs. These only sound hard. If you won't have enough time to make and fill the puffs during the program, bake them in the morning, and allow participants to cut them open, and fill them with custard, whipped cream, cherries, chocolate, or whatever you wish.

Pasta. If you have a pasta machine, know how to use it, and your sauce is already made, a group of sibs can turn flour and eggs into homemade spaghetti or fettucinne in less than an hour. It cooks in seconds. Don't forget candles and Italian bread!

Pizza. Before putting them in the oven, allow sib chefs to customize their slices of pizza with a variety of toppings.

Ice cream. A time-honored method of channelling excess energy is to crank an ice cream freezer. Making ice cream is as educational as it is rewarding. We're always surprised at the number of children who've never made or had homemade ice cream before.

Special Guests

Surprises can help keep Sibshops lively. One surprise we've used successfully is special guests, who come to the program to conduct a mini-workshop with participants. These guests, who often donate their time, have included a 15-year-old street juggler who taught us some of the basics of his craft; a mime who showed us how to get trapped in an imaginary room and, equally important, how to get out; and identical-twin folk singers who led participants and their special siblings in sing-a-longs and dances, and sang some funny songs about being brothers.

As with many Sibshop activities, you are limited only by your imagination in choosing a special guest. Chefs who can show sibs how to make a special dish or dessert, clog or tap dancers who are willing to perform and teach a step or two, gymnasts, or even a local football hero who would enjoy playing touch football with admiring participants are some examples of other special guests you can invite to help make your Sibshop a really memorable event.

The Sibshops we have offered for young siblings and their parents at the Experimental Education Unit have been extremely rewarding. Speaking for ourselves, we have learned first hand, from the siblings themselves, what it's like to grow up with a child who is handicapped. We have been impressed again and again with the sensitivity and creativity these young siblings have displayed as they talked about their special brothers and sisters, their parents, and their personal approaches to some very delicate and difficult situations. Siblings have much to share, and we cannot emphasize too strongly that professionals have much to learn from these young family members. The immediate goal of the Sibshops is to help siblings learn from one another, but we often wondered if we professionals weren't reaping the greatest benefits. Those of you who offer workshops for siblings will no doubt share these experiences, and will become, like us, ever more respectful and impressed with the range of problems siblings experience, and their personal resourcefulness in coping with their experiences. As we have said earlier, the activities we have described were successful for us in eliciting those experiences and coping strategies, and in fostering mutual supports among siblings. We offer them as a starting point for others, and we welcome your feedback on how well they work for you, and how you have varied or added to this framework to better meet the needs of your populations.

Siblings are the primary audience for these workshops, but in the parent discussion activities, we try to share information on sibling concerns with parents. Sibling concerns have been neglected by professionals, who often

have little direct contact with siblings, but they often also remain a mystery to siblings' parents, both when children are young and unable to articulate their feelings, and when they approach adolescence and become more reluctant to do so. For this reason the sibling panels for parents have proven to be doubly valuable in our programs. First, the panels give parents an opportunity to find out what a sibling feels and thinks without violating a son's or daughter's privacy. Parents can ask older siblings questions that will help them prepare for their younger son's or daughter's future. Second, the panels have also revealed to us the questions that parents have about their nonhandicapped children, and their often serious concerns whether they are doing the right thing for all of their children. These insights have helped us provide parents with the information they need to better understand their nonhandicapped children, and to balance their family's needs.

We offer this handbook to other professionals in the hope that you will begin to serve the young siblings in your communities. All of us who work with handicapped children appreciate the benefits of supporting the family to provide a nurturing environment for the child. Family supports also enable members to cope with the added daily and long-term stresses they face. Programs for siblings recognize the needs of one group of family members who often bear significant responsibilities in these families. The activities we have outlined have been beneficial for us and the young children we have served. We hope that they will offer similar benefits for other groups of siblings, and we look forward to learning more about the kinds of programs others offer to serve these special siblings of children with special needs.

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Appendix A

Books About Handicaps for Young Readers

Autism

The devil hole by Eleanor Spence. Lothrop, Lee and Shepard, 1977.

The October child by Eleanor Spence. Oxford University Press, 1976.

Please don't say hello by Phyllis Gold. Human Sciences Press, 1976.

Blindness and Visual Handicaps

Belonging by Deborah Kent. Ace Books, 1979.

Listen for the singing by Jean Little. E. P. Dutton, 1977.

Being blind by Rebecca Marcus. Hastings House, 1981.

Tom and Bear by Richard McPhee. Thomas Y. Crowell, 1981.

Laurie by Diane Greig and Alan Brightman. Scholastic's Feeling Free, 1978.

Connie's new eyes by Bernard Wolf. Harper and Row, 1976.

Sally can't see by Palle Petersen. John Day Company, 1977.

Spectacles by Ellen Raskin. Connecticut Printers, Inc., 1968.

The seeing summer by J. Eyerly. J. B. Lippincott, 1981.

Cerebral Palsy

Let the balloon go by Ivan Southall. Methuen, 1968.

Mine for keeps by Jean Little. Little, Brown and Company, 1962.

Howie helps himself by J. Fassler. Albert Whitman and Company, 1975.

Deafness and Hearing Problems

Silent dancer by Bruce Hlibok. Messner, 1981.

Apple is my sign by Mary Riskind. Houghton Mifflin, 1982.

The swing by Emily Hanlon, Bradbury. 1979; Dell, 1981.

A show of hands by Mary Beth Sullivan and Linda Bourke. Addison-Wesley, 1980.

A button in her ear by A. Litchfield. Albert Whitman and Company, 1976.

I have a sister, my sister is deaf by Jeanne Whitehouse Peterson. Harper and Row, 1977.

Lisa and her soundless world by Edna Levine. Human Sciences Press, 1974.

Claire and Emma by Diana Peter. Adam and Charles Black, 1976.

Emotional and Behavioral Handicaps

Walkie-talkie by Phyllis Green. Addison-Wesley, 1978.

Mad Martin by Patricia Windsor. Harper and Row, 1976.

Epilepsy

Epilepsy by Alvin and Virginia Silverstein. J. B. Lippincott Junior Books, 1975.

A handful of stars by Barbara Girion. Charles Scribner's Sons, 1981.

What if they knew? by Patricia Hermes. Harcourt Brace Jovanovich, 1980.

Language Problems

Trouble with explosives by Sally Kelley. Bradbury, 1976.

I can't talk like you by Althea. Dinosaur Publications, 1982.

Physical Handicaps

Ginny edited by Alan Brightman and Kim Storey. Scholastic's Feeling Free, 1978.

Hollis edited by Alan Brightman and Kim Storey. Scholastic's Feeling Free, 1978.

Hackett McGee by Charles Grealish and Mary Jane Grealish. Scholastic's Feeling Free, 1978.

Alesia by Eloise Greenfield and Alesia Revis. Philomel, 1981.

Wheelchair champions by Harriet May Savitz. Harper and Row, 1978.

Sports for the handicapped by Anne Allen. Walker, 1981.

Run, don't walk by Harriet May Savitz. Accent Special Publications, 1979.

Physical disabilities by Gilda Berger. Franklin Watts, 1979.

Mister O'Brien by Prudence Andrew. Heinemann, 1972.

Mark's wheelchair adventures by Camilla Jessell. Methuen, 1975.

Spina Bifida

Janet at school by Paul White. Adam and Charles Black, 1978.

Learning Disabilities

Keep stompin' till the music stops by Stella Pevsner. Seabury, 1977.

But I'm ready to go by Louise Albert. Bradbury, 1976.

Kelly's creek by Doris Buchanan Smith. Harper and Row, 1975.

My brother Barry by Bill Gillham. Andre Deutsch, 1981.

'I own the racecourse!' by Patricia Wrightson. Hutchinson, 1972.

Mental Retardation

Welcome home, Jellybean by Marlene Shyer. Granada, 1981.

The Alfred summer by Jan Slepian. Macmillan, 1980.

He's my brother by Joe Lasker. Albert Whitman and Company, 1974.

My brother Steven is retarded by Harriet Sobol. Macmillan, 1977.

A look at mental retardation by Rebecca Anders. Lerner Publications, Minneapolis, Minnesota, 1976.

Don't take Teddy by Babbis Friis-Baastad. Charles Scribner's Sons, 1967.

The summer of the swans by Betsy Byars. Viking Press, 1970.

A racecourse for Andy by Patricia Wrightson. Harcourt, Brace, and World, 1968.

Take wing by Jean Little. Little, Brown, and Company, 1968.

Mary Fran and Mo by Maureen Lynch. St. Martin's Press, 1979.

My sister by Karen Hirsch. Carol Rhoda Books, Minneapolis, 1977.

A special kind of sister by Lucia Smith. Holt, Rinehart, and Winston, 1977.

She's my sister by Jane Claypool Miner. Pitman Learning, Inc., Belmont, California, 1982.

The blue rose by G. Klein. Lawrence Hall and Company, 1974.

A place for everyone by Tana Reiff. Fearon-Pitman, 1979.

Sticks and stones by Lynn Hall. Follett, 1972.

Between friends by Sheila Garrigue. Bradbury, 1978.

It's too late for sorry by Emily Hanlon. Bradbury, 1978.

Don't forget Tom by Hanne Larson. Thomas Y. Crowell, 1978.

A little time by Anne Norris Baldwin. Viking Press, 1978.

The hayburners by Gene Smith. Dell, 1975.

General Books About Handicaps

Friends by Melva Jackson Edrington. Instructional Development Corp., P.O. Box 361, Monmouth, Oregon, 97361, 1978.

Like me by Alan Brightman. Little, Brown and Company, 1976.

What if you couldn't ....? A book about special needs by Janet Kamlen. Charles Scribner's Sons, 1979.

Who will take care of me? by Patricia Hermes. Harcourt Brace Jovanovich, 1983.

The raft by Alison Morgan. Abelard-Schuman, 1974.

What do you do when your wheelchair gets a flat tire edited by D. Biklen and M. Sokoloff. Scholastic Book Services, 1978.

Like it is: Facts and feelings about handicaps from kids who know by Barbara Adams. Walker, 1979.

Winners: Eight special young people by Dorothy Siegel. Messner, 1978.

Feeling free by Mary Beth Sullivan, Alan Brightman, and Joseph Blatt. Addison-Wesley, 1979.

About handicaps: An open family book for parents and children together by Sara Bonnett Stein. Walker, 1984.

Health, illness and disability: A guide to books for children and young adults by Pat Azarnoff. R. R. Bowker, 1983.